DOCUMENT RESUME

ED 307 774 EC 220 283

AUTHOR Gustavsson, Anders
TITLE Ideals of Society and Parental Responsibility.
PUB DATE Aug 88
NOTE 10p.; Paper presented at the International Conference on Family Support (1st, Stockholm, Sweden, August 14-19, 1988).
PUB TYPE Reports - Descriptive (141) -- Viewpoints (120) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Conflict Resolution; Counseling; Decision Making; Disabilities; *Emotional Adjustment; *Family Problems; Fathers; Foreign Countries; Individual Development; Interviews; *Mental Retardation; Mothers; *Parent Attitudes; Quality of Life
IDENTIFIERS Sweden

ABSTRACT

The paper describes the conflict between parental responsibility for a handicapped child, particularly a retarded child, and the parents' other interests and concerns. Swedish parents (N=60) of retarded children were interviewed once and three families were interviewed several times over a 6-month period. Parents typically went through a period of trial and error before finding their own style of living with the handicapped child. Phases in this process typically involved discovery, meeting the new life situation, personal solution, and retesting. Mothers and fathers were often affected differently by the conflict between their own needs and the child's needs. Sample dialogue from the interviews is included to illustrate the study's conclusions. A third study, involving 47 of the original group, examined effects of group and family counseling. This study found that counselors were unable to give parents direct advice in finding suitable personal solutions, though parents were helped by a reduced sense of deviation, a deepened insight into their own family situation, and increasing awareness of resources for finding personal solutions. (DB)

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ED307774

THE FIRST INTERNATIONAL CONFERENCE
ON FAMILY SUPPORT

STOCKHOLM 1988

IDEALS OF SOCIETY AND PARENTAL RESPONSIBILITY

ANDERS GUSTAVSSON, Phd

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IDEALS OF SOCIETY AND PARENTAL RESPONSIBILITY

The aim of this paper is to describe an insoluable conflict between parental responsibility for a handicapped child and the parents' other interests and projects. One of the points of departure for the study that led to the discovery of this conflict was my own work with different kinds of support to families with mentally retarded children. From 1975 - 1985 I organized municipal support to families with children who had different sorts of handicaps. What I learnt from this work was the variety of problems that parents in such families face, wich stimulated my interest in how to understand these problems. Existing theories and other published experiences of what it is like to have a mentally retarded child, seemed to leave important parts of the parents' difficult situation unexplained (Farber 1960, Solnit & Stark 1961, Birenbaum 1968, Erikson & Hall 1974, Kew 1975, Cullberg 1975, Schmid 1977).

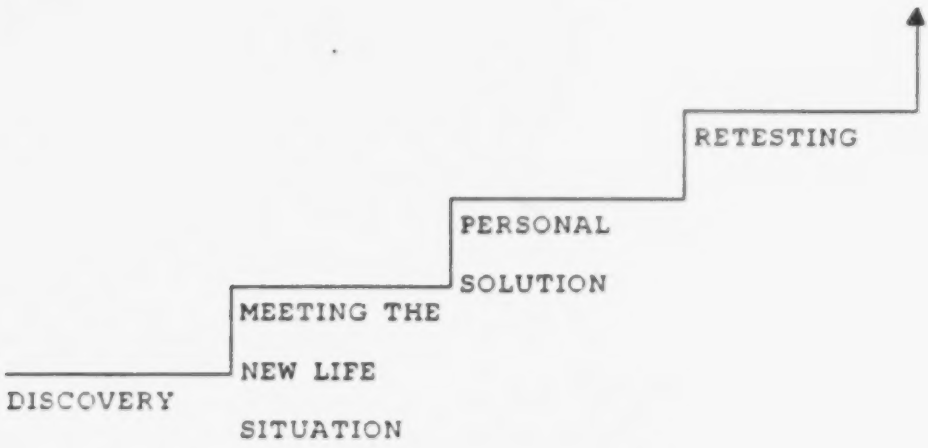
The purpose of my study (Gustavsson 1985) was to further the understanding of what it means to have a mentally retarded child. To this end I have studied 60 parents with children aged 0 - 8. First three families from three of Stockholms suburbs were selected from a total group of parents with mentally retarded children of this age group. These families were interviewed in depth several times over a six month period. Moreover I observed them frequently in their homes as well. Because I assumed that the meaning of the mental retardation changes over time, I contacted one family which had recently been informed that their child was retarded, and one family which had known about the handicap for several years. Both these families looked after thier child at home. The third family I selected however had placed it's handicapped child in care outside the home.

The information gleaned from these three families was later compared with and supplemented by information which I gathered from interviews with the rest of the parents with mentally retarded children 0 - 8 years old, living in the suburbs mentioned above and from interviews with parents of such families in three small country towns. Of the existing 36 families in the six towns, 31 agreed to participated in the study. These parents described their situation in an approximately two hour long dialogue with me. The extensive information that I collected was qualitatively analyzed.

The qualitative analysis was inspired by earlier work in my research group that has done several studies on social problems of minority groups and disabeled persons. One of the basic ideas underlying the approach of these studies was that it is possible to understand people's experiences, intentions and actions when one discovers the life conditions of these people, the way they themselves see them(Ricoeur 1971, Trankell 1973, Ödman 1977). As a starting point of my analysis of the parents' situations I therefore took the parents' descriptions of their own families. When

I analyzed these discriptions of the parental conditions, I found certain similarities. It became apparent that all of the parents went through a process of trial and error until they found their own special style of living with their handicapped child. Several different phases could be distinguished in the process, which can be illustrated as a flight of steps without an end.

Personal development



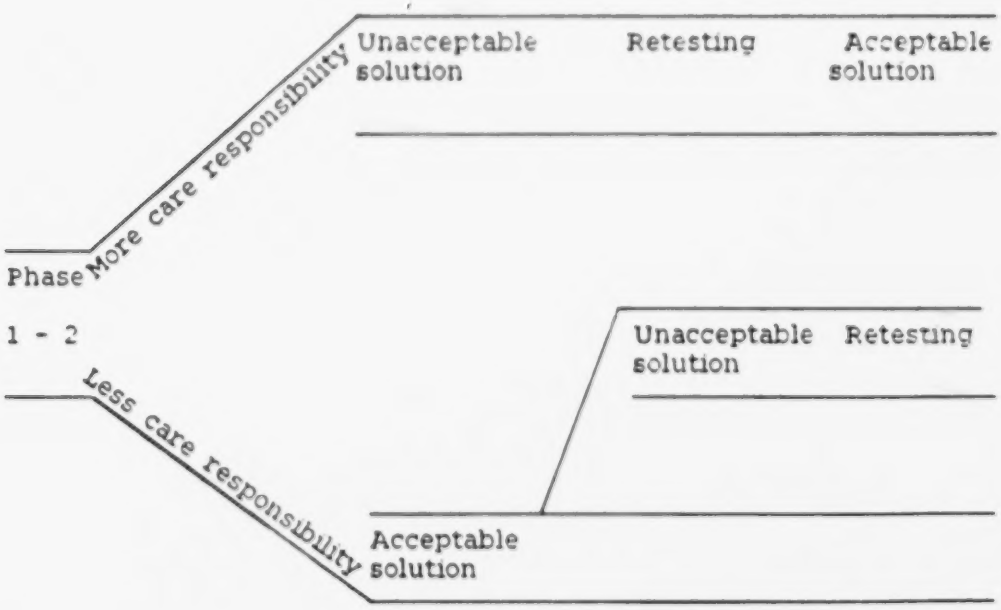
The first phase(DISCOVERY) was characterized by the parents feeling that their whole existence was shattered when they realized what had happened to their child. During the second phase(MEETING THE NEW LI SITUATION) they began to understand what importance the handicap ha for the child and the impact on their own lives. It was then that they realized that their opportunities of creating a new meaningfull life, based on the changing conditions within the family, were limited by the fact that they had landed in an insoluable conflict between their own personal interests and those of their handicapped children. In order to provide the child with the care they felt it needed they were in fact forced to abandon some of their own life projects, i e the plans and ambitions they had for their lives. Whatever priorities they made they felt that they had either betrayed their child or themselves. One father described his responsibility conflict like this:

SVEN: And then we have the question, how much are you willing to sacrifice of yourself and your own ambitions for your child. This is an ethical, humanistic question. What is our task here? Is it to give birth to children and to do everything for them or is it to realize our own lives, to have a life of our own. That valuation is hard to make.

However, all parents came to some solution(PERSONAL SOLUTION, phas three). The inevitable losses they were thus forced to endure led them in time to reject their first solutions and to test new ones(RETESTING, phase four) The remaining phases, different amounts for different parents, consisted of testing various personal solutions until they found an acceptable way of living with the family's problems.

The insoluale conflict affected in many cases the lives of the mothers and fathers in different ways because it was the mother who took care of the child. Therefore she was more often severely hit by the child's handicap than the father was. Some of the fathers were able, at least in the beginning, to avoid the conflict of responsibility and therefore did not have much difficulty in finding a way of living with their handicapped children. As time went on, however, some of them were often forced to take part in the conflict because they realized how much their wives had to go without and the men felt responsible to help out. Then fathers were also forced to test their own compromises between their own and their child's interests.

Two directions of the personal development



Many of the parents I got to know managed as time went on to find a way of living with the responsibility conflict by trying to find a temporarily acceptable compromise between their child's and their own personal interests. They were, however, able to reach such a compromise only after they had gone through a maturation process. This meant that they mourned the losses of the life projects they had abandoned and formulated new ones which were grounded in a new personal ethic. The maturational process also meant that they succeded in finding a way of integrating their new parental identity in their self image without having to diminish their self respect. Because the compromise that the parents eventually achieved was always based on conditions which momentarily existed in the family, it worked only as long as these conditions did not change. When this happened, e g when the child grew older, the parents were again forced to try to find yet another acceptable personal solution. Then there is a great risk that they will be forced to struggle with the responsability conflict for the rest of their lives.

Even though the discovery of the parents personal dilemma and personal development increased my understanding of their situation, I found it necessary to extend the scope of my study. In the first place the parents' own descriptions of their resposibility conflicts were not sufficient if one wanted to understand what lay behind the experiences and behaviours characteristic to their struggle with their new life conditions. In the second place, I had a feeling that the parents' responsibiltity conflict was influenced by the social and medical authorities. One father I interviewed told me this;

TOMAS: The staff at the hospital suprisingly showed great interest in our situation as long as we were still in the maternity ward. They gave us information about all the services avalable. And, as I saw it, they encouraged us to take the child home and not to reject it and say that we didn't want...But, after we did so - and I felt this sc deeply - the silence was dreadful. No longer was anyone interested or supportive of our decision to take the bay home. It was as if - the staff could rest easy - now they'd done their job. They'd coerced us into taking total responsibility for our handicapped child so that no-one else would have to be resonsibel.

This second study provided a view of how society influences the parents' situation because these authorities' goals and actions reflect ideals and norms prevalent in society at large. I interviewed personnel employed in social and medical services. The answers showed that these official institutions had an important influence over the parents' responsibility conflicts. In our society a mentally retarded child is in fact not only the parents' responsiblity, but also to a very great degree there are officials who are responsible for the society's support of the child. This means that these children live in a field of tension between parental and official responsibility and that parents who have such children are strongly influenced by those who shoulder societal

responsibility for handicapped children. The influence of personnel on the parents meant that they tried to induce them to adjust their lives to the needs of their children, which in the first place manifested itself in the fact that they persuaded them to look after their children at home.

This method of working was due to the fact that the personnel were anxious to implement the authorities' official goal for the handicapped child. This goal was based on a care ideology which developed during the 1950s and 60s whereby all mentally retarded would be able to live as normally as possible in society. Because this goal is incompatible with parents sending their children away to institutions or foster homes, the personnel were forced to intervene in their formulation of responsibility for these children if they arrived at such a decision. Personnel who did not represent the interests of the child ran the risk of being regarded as incompetent and immoral. As many of them hade identified themselves with the authorities's ideals they also thought that they betrayed themselves if they set the official goal aside. One social worker told me about a conflict she had struggled with when she was pregnant.

BRITT: The first time I was pregnant my only thought was to have a normal child. The second time it was different. Then I was in agony, I thought... What should I do? What if the baby is handicapped? As a counselor I should... I know what I ought to do, I should keep the child home of course, I should manage and so on. At the same time, would I really do it?

However, only a few, of those I interviewed consciously tried to direct the parents. They did not in fact see that their exertion in trying to put into practice their goals for the child imposed an unintentional influence on the parents. Many of them also reformulated the goal for the child in terms of goals for the parents, which dampened the anxiety they felt when faced with breaking the norms that people have the right to make their own decision about their own lifes. The influence of the authorities over the parents had however never been as strong as it was if the goal for the handicapped child had not been in agreement with one of our culture's basic moral codes, namely that parents ought to look after their children themselves.

The discovery of how personnel working for the medical and social services intervened in the parents' formulation of responsibilities for the child radically changed my view of their situation. I realized that the responsibility conflict was not merely personal, but also a manifestation of the parents' difficulties in fullfilling the demands made on them by the authorities. Against this background I felt it was important to examine more closely how society influences the parents' situation. In that connection I discovered that the responsability conflict in its entirety can be seen as a manifestation of the fact that the parents are not able to live up to the demands made on them by society in different situations. I

discovered in fact that the conflict was not only influenced by the curent ideology for support to handicapped children, but just as much by the fact that society places demands on us as adults that we must have a good education, compete in the labour market, be good husbands/wifes e t c. This means that the parents I studied were forced to try to live up to different societal ideals which were in fact incompatible. On the one hand, they should be good parents even to a handicapped child, on the other hand they must live up to the demands made on a normally successful man or woman in other areas. Consequently the responsibilty conflict is not only a manifestation of the parents' own conflicting desires, but also of the fact that they try to live according to incompatible norm systems.

That the parents followed the recommendations of the authorities was to a great extent due to the fact that they adopted the ideals of the personnel and made them their own. By implementing a socially anchored parental ideal they could reduce the consequences of the social stigmatization of which they were object. Their relationship with their children meant in fact that they had to accept part of the stigma which all mentally retarded carry. It was thus in the interest of the parents that they lived up to the ideals the authorities presented. Consequently, that they adjusted themselves to this ideal was not solely due to the fact that they passively yielded to the influence they were exposed to, but at least as much because they could in this way escape from a much worse fate, namely that they might lose their identity as normal men or women.

Furthermore, stigmatization influenced both the parents' way of regarding the reponsability conflict and the type of solutions they chose. In fact they often regarded their stigma as a sign that they had failed as parents, which made them extra vulnerable when they were forced to choose betweend being a good parent and living up to the demands they met in other areas. An important explanation as to why nearly all parents chose to look after their children themselves is therefore that they felt they must first and foremost take responsibilty for their children, in order to reduce the consequences of stigmatization.

Fourty seven of the 60 parents who took part in the first two studies also took part in a third study (Gustavsson 1988) where I focused on the possibilities of support to parents, through group- and family-counseling, in their personal development. Three groups were formed. Each consisted of about ten parents living in the same area and the purpose was to give them opportunity to share experiences with each other. Two social workers, with experience of supportive groups for parents with handicapped children led the group sessions. The groups met at seven occassions during a period of six months.

Ten families were given family-counseling. One experienced counselor met with the mother and the father in each family for six or seven times to discuss their specific problems with the retarded child and what could be done to solve them.

The value of the support was estimated both by the parents themselves and by the counselors. Only those parents who indicated valuable experiences that were confirmed by the counselors, were considered to have been positively influenced by the counseling. These results were then analyzed from the standpoint of my earlier findings of the parents personal development.

Of the 47 parents that participated in either group- or family-counseling, 28 were found to have recieved support in their personal development. Seventeen of them participated in the parental groups (in all 32 parents participated in groups) and 11 had had family-counseling (totally 15 parents had family-counseling).

However, the most important results concerns the nature of the supportive process. I found that it seemed to be impossible for a counselor to give the parents direct advice in finding suitable personal solutions. In fact the support that the 28 parents recieved hadn't in any way changed their personal priorities between their care for the child and other life projects. The value of the support instead consisted in that it increased the parents' resources to experiment their way towards their own personal solutions.

The group- and family-counseling increased the 28 parents' resourses to deal with their problems in four ways. Most frequently the support consisted in a reduced sense of deviation and a sense of being more normal. This effect was experienced first of all by the parents participating in the groups and it seemed as if the being together with other parents of mentally retarded children, reduced the effect of the stigmatizing process that they whad experienced.

Another valuable experience that rather many parents had was that their insight into their own family situation was broadened and deepended when they discussed it with the counselors and the other parents. The two remaining valuable experiences were that the some parents got new information about mental retardation and about other parents ways of handling problems. To some of them(mostly those who had family-counseling) the counseling sessions also meant increased possibilities to discuss the family situation with their wife/husband.

Another interesting result was that attempts from the counselors to directly influence the parents' ways of handling their problems, often lead to defensive reactions from the parents. Parents who left the program before it was finished(9 of 47), e g often did so as a reaction against the counselors or the other parents trying to influence their personal solutions.

These defensive reactions and the discovery, that the parents can only be helped by means of increasing their resourses to find their own personal solutions, can be understood against the background of the parents personal development and their responsability conflict that I have decribed.

In order to learn to live with the handicapped child, the parents must by trial and error find their way to a personal priority between their ambitions for the child and their other life projects. Each parent's ambitions and life projects are unique and can only be fully valued and understood by the parent himself. Furthermore, the only way to find an acceptable way to live with the dilemma is through a process of personal maturation, were you give up some earlier life projects and adjust your personal ideals to the your present family conditions. As a result of this, the parent's personal development must be guided by his or her interpretation of the family situation and intentions of how to handle the problems with the retarded child. An adequate support for the parents therefore must focus on increasing the parents' own resourses instead of guideing them in how to do. It is also important to have respect for the parent's own intentions and solutions, whatever they are, instead of trying to advise them on how to form their own and their childrens' life.

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